Legislative Assembly for the
Australian Capital Territory
Standing Committee on Social Policy

Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

Submission number: 027

Submitter: Name withheld

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RE: Inquiry into endometriosis and other pelvic pain conditions

I am pleased to see this issue being considered by the Committee.

Endometriosis destroyed my body, my mind and my sense of self. It took me 23 years to be formally diagnosed and treated, and in that time I suffered from excruciating pain; degrading medical experiences; medicine that changed my body and my relationship with it; financial and professional consequences; and all while navigating a world that does not particularly care about women.

Now in my mid-30s, I am finally in a position where my endometriosis is manageable, I experience relatively low amounts of pain, and it no longer greatly impacts my life. However, I would like to share with you the difficulties I faced in achieving this. This is my personal experience but I have found it is not atypical among women diagnosed with endometriosis or similar conditions.

Terms of Reference – 2: the barriers in the ACT to getting a diagnosis and gaining access to treatment including primary care, specialist clinics and ongoing pain management for these conditions

I lived in Melbourne until 2017, however I have found women's experiences in diagnoses and treatment to be similar regardless of jurisdiction. I was fortunate that my family was supportive and took my symptoms of severe, debilitating pain seriously.

They took me to doctors (who insisted the pain I felt was normal), they took me to hospital (where I was consistently tested for appendicitis or treated as drug seeking), and they paid for specialist appointments.

Despite this, it took me from the age of 11 to 22 before a doctor (a GP who specialised in women's reproductive health) suggested I may have endometriosis.

At no point has any doctor in Melbourne or Canberra offered any support for pain management; I have been on and off roughly 6 different types of birth control, which have invariably failed to work and caused significant side effects.

Every single pain management tool and technique I have developed has been through trial and error, and from discussions with other women experiencing similar symptoms.

Specialists in Canberra in particular have extremely long waitlists, if their books are open at all. I have been fortunate to find medical practitioners who specialise in women's health, and who immediately accepted my descriptions of pain, agreeing that it was likely endometriosis. Despite this, it still took me four years to obtain treatment.

Terms of Reference – 3: the treatment options and supports available in the ACT compared to other jurisdictions, their evidence-based effectiveness and potential side effects and impacts

Regarding endometriosis, there are few medical options available, regardless of jurisdiction. Medical studies into it, and similar conditions, are still developing, with the majority of research so far directed at the impact such conditions have on male partners. The 'gold standard' treatment is laparoscopic surgery to excise any identified endometriotic tissue.

In Canberra, there are not many surgeons who take such patients; most of them operate privately, and are expensive. There are excessive delays to access public care and communication is thin on any progress.

In 2019 I was referred to the Canberra Endometriosis Centre with a strong recommendation from my GP that I undergo surgery. My physical and mental health were deteriorating due to pain and my GP was increasingly concerned, as the pill had ceased working and I was experiencing PPMD (Premenstrual Dysphoric Disorder) that was causing suicidal ideation.

I was considered a Category 2 for endometriosis surgery; this meant I was supposed to be seen within 90 days, and that my need for surgery should be considered semi-urgent. It meant I had a condition that was causing me undue pain and disability.

Understandably, there were delays due to COVID-19. However, between my referral in 2019 and my eventual appoint in 2024 at the Centenary Hospital for Women and Children Gynaecology department, I only ever received two phone calls to ask if I wished to remain on the waitlist. I was also advised that I was not a high priority, a statement that did nothing to reassure me that women's health and wellbeing was taken seriously.

My appointment at the Centenary Hospital for Women and Children Gynaecology department was only a consultation with a nurse practitioner; while she was fantastic and very empathetic, it was made clear that I had exhausted all the lifestyle measures available, and that surgery was now my best, and only, option. I was told that it could be another 12 months of waiting before a consultation with a surgeon was available. By this stage, my physical and mental health were deteriorating; I could not wait another 12 months for merely another consultation.

The nurse explained that the centre had not been permitted to see any patients for endometriosis during the pandemic, and was attempting to catch up with the ever growing waiting list. I was horrified, although unsurprised; women's health is often a low priority and easily overlooked in times of crisis.

Terms of Reference – 4: the role of medical misogyny, underlying gender biases in healthcare and cultural norms that create barriers for women with these conditions

I first saw a doctor regarding the pain I experienced when I was 12 years old. My parents and I were assured it was normal, that all women experienced period related pain, and it was suggested that I was merely sensitive – perhaps a bit of a cry-baby, and probably looking for attention.

When I was only 14 years old, a GP advised my mother and I that there was no need to address my pain as it would go away once I became pregnant; aside from being incredibly unhelpful, I later learned that women with endometriosis and similar conditions can struggle to get pregnant.

When I was 15, on a school wilderness camp, I fell through a rotten log and broke my ankle. Assuming it was merely sprained, and as a self-conscious teenager unwilling to make much fuss, I then proceeded to walk on it for a week. It turned out that I had torn the ligaments in my ankle and snapped a small bone in the joint. The surgeon I was referred to was shocked that I had been able to walk, and when I explained that the pain had simply not been as severe as my period (pain levels I had been told for years was normal), he assured me that this was abnormal and wrote to my GP.

This was a turning point in medical professionals beginning to take my pain more seriously. However, despite a letter from a fellow medical professional, my doctor just advised me to take a specific painkiller, Ponstan. This did help dull the most severe of the pain I experienced, but by the time I was 20 years old, I had developed a reaction to the drug which to this day, makes me vomit. My pain levels continued to grow.

At 21 I was sent for my first internal ultrasound, although I now know they most often cannot detect endometriosis. The internal examination, at a local imaging centre, was uncomfortable and invasive. I was told to strip almost entirely naked and left alone with a male technician who was rough, rude, and blamed me for the poor quality of the image produced. I left trembling and in tears. Many years later, at a much more sympathetic appointment at the Canberra Fetal Assessment Centre, I was gently informed that this experience was tantamount to sexual assault; I was not merely a silly girl overwhelmed by a new experience. My lingering fear, indignity, aversion to medical treatment and mistrust of male medical practitioners was valid, according to her; as one of the 61% of women with endometriosis who experience dyspareunia (pain during sexual intercourse), the lack of care while being subjected to such an invasive procedure horrified her.

Terms of Reference – 5: the economic and social impacts of people in the ACT with these conditions, including education, employment and lost productivity

While in university, the pain, already unbearable, increased. I started getting headaches from the birth control and struggled with a full time courseload and a casual retail job. I had to obtain medical certificates to excuse myself from classes, at my own expense, and lived in constant fear of my period coinciding with exams.

Depending what variation of the pill my body would tolerate, the cost has ranged from $80 to $30; each medical certificate had the added cost of a medical appointment, at $150. Imaging costs were close to $300 each time; an MRI before I had surgery was close to $500. Gynaecologist appointments ran between $250 to $500; surgery was in excess of $2,000, and I was fortunate to have excellent private health coverage.

There is the hidden cost of painkillers; of heat pads and wheat packs; of imported aids, because the Australian market offers little in the way of home medical equipment. Of a TENs machine and refills, of pads and navigating the world of snake oils that promise women relief from pain so severe they can become desperate.

Before surgery, I lost at least two days a month – often these fell on a weekend, but just as often it was during a work day/s. I was often asked by managers to account for me ‘excessive’ leave, told no one else needed so much time off so consistently, and it was even suggested I seek mental health support to ‘manage’ my ‘need’ for sick days. Most managers were not sympathetic or understanding of the reason why I needed this leave; male managers in particular suggested it was ‘inappropriate’ to discuss menstruation in the workplace, even if it had only come up because they demanded to know why I needed to take personal leave.

The actual days that were agonising, and which left me unable to function at even the most basic of tasks, do not fully capture the impact. In reality, I spent a week before my periods slowly downing with PMSS symptoms, my mental health so poor that I contemplated suicide. After my period was finished, it would take me almost a week again to recover from the physical toll on my body, exhausted from surviving so long in absolute agony. Out of a whole month, I was lucky to get a single week where I felt normal.

Terms of reference – 6: education available to medical professionals, allied health professionals, young women and others, on these conditions and treatment options

There has been a huge increase in awareness, knowledge and specialisation since 2000. Now, most doctors appear to be aware of the condition, and understand it is a serious issue. However, there is still a lot of work to be done with treatment options and the availability of experts.

There is, however, a gap between medical professionals and the wider community. While there is growing awareness, most women are still expected to self-advocate and have to practically become experts in order to educate those around them. Employers in particular, even when sympathetic to the concept of endometriosis and pelvic pain, are rarely cognizant of the reality of such conditions and even more rarely prepared to support an employee who may require accommodations.

Terms of reference – 8: any other related issue.

While it's fantastic that the Australian government, state and territory governments, and the medical profession are now seriously investing in researching and responding to these conditions, the fact that it has taken so long, that the average time to be diagnosed is still over 5 years, and that the main form of treatment is still limited to contraception, is infuriating. I will require further surgery in about 5 years, with all the risks and recovery that requires; there is no cure, no accommodations, almost no support aside from the networks women make themselves; and the impact on women's lives is still so often downplayed to how to affects their families, partners and ability to be productive.

Many women still have to lie and claim they have concerns about conceiving to receive tests; they have to bring their husbands to appointments to ensure they are listened to; and when they do finally receive referrals and undergo testing, it is often invasive, painful and delivered with condescension. The experience men have in receiving medical care is startlingly different. As an example, a male friend underwent an invasive cystoscopy procedure; advised it would be done without a general anaesthetic, he was nervous. As his female friends, many of us were quick to provide tips and advise on managing similar pain – taking paracetamol and ibuprofen in advance, having heating or ice packs, breathing techniques etc. On the actual day, he received a local anaesthetic, numbing cream and was sent home with a week's supply of codeine based painkillers. None of us had ever been provided with such an excellent standard of pain care. While none of us begrudged him, it was a dispiriting reminder of the gulf between how seriously men's experiences with pain are treated by the medical community, compared to women's.

I am now older, better informed, and have identified a solid medical support system that is supportive of my medical needs. I am in therapy to help me come to terms with my experiences, and am in the process of unlearning years of pain, that have re-wired how my brain interprets pain and made my muscles permanently tense. I swim, I do yoga and acupuncture, and I am finally learning to love my body, rather than feel betrayed by it.

More needs to be done to support women experiencing pelvic pain; it needs to be acknowledged that it impacts their whole bodies, lives and mental health. There needs to be more funding so women are not waiting years for help and more training for medical professionals. There needs to be information for employers and specific workplace protections in the law for women, particularly noting the length of time it can take for diagnosis and the difficulty in obtaining treatment.